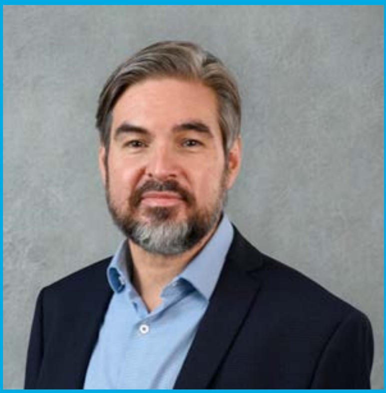
Annual Conference Report 2025

Saturday 26th April 2025
Hilton, Northampton

bbs uk
Bardet-Biedl Syndrome UK

Conference 26: Save the Date!

25-27 September 2026



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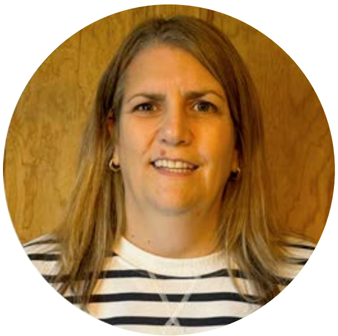


On behalf of the BBS UK team, I am delighted to share with you a report from our 32nd Annual Conference, held in Northampton on Saturday 26th April 2025.

It was a privilege to have so many of you join us for a day filled with insightful discussions, knowledge sharing, and the strengthening of our community ties. We had 235 registrations for the conference weekend, with 168 delegates for the conference programme on the Saturday. We were also joined by attendees across the UK and abroad, who tuned in through the livestream.

This was my first BBS UK conference, and I was delighted to meet so many families as well as to hear first-hand from many of you how essential the support from the Charity has been.

This year's event featured a comprehensive program, showcasing diverse presentations from leading experts in the field. We had the pleasure of hearing from renowned specialists who shared the latest research developments, clinical advancements, and practical advice on managing BBS. A crowd favourite are the personal perspectives which resonate with so many of us; we are incredibly grateful to those who shared their journey with us in this way.

Summaries of all the presentations and personal perspectives can be found within this report; the full recordings can be found on the BBS UK YouTube channel and accessed via our website.

To our speakers, we extend our heartfelt thanks. Your expertise and dedication are invaluable to the BBS community, and your contributions have greatly enhanced our collective understanding and support for those affected by Bardet-Biedl syndrome.

BBS UK is here to support all those living with the Syndrome, their families and carers and the professionals involved in their care, and relies on the generosity of our supporters to continue providing vital services, including this annual conference.

If you would like to contribute, information on how to make a donation or become a 'Friend of BBS UK' can be found on the Support Us page on our website.

As you will read, the Charity has so much to offer in terms of information and support services so please do stay connected, make sure that you are on the mailing list to receive news, and we really hope to see you at future events.

Emma Hughes
Chair, BBS UK

SAVE THE DATE:

Planning has already begun for Conference 2026, which will be held across the weekend of 25th - 27th September 2026. Further details will be available on the BBS UK website next year.

We look forward to seeing you there!

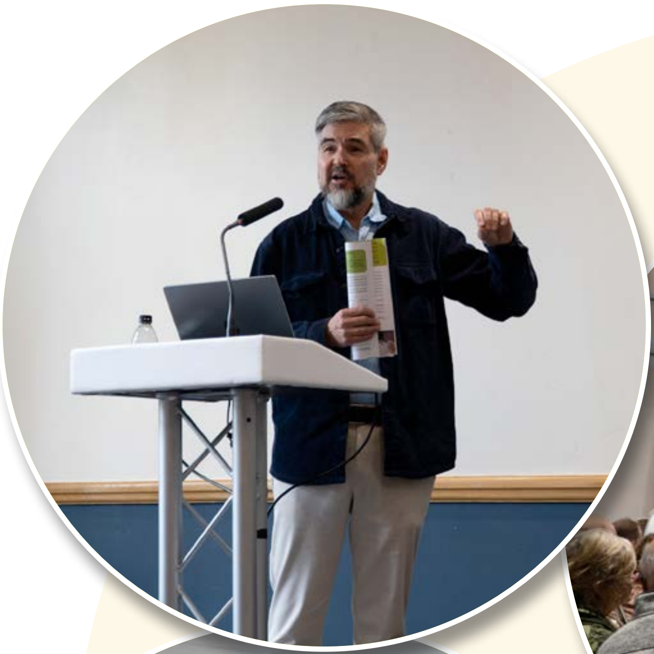
Update on Gene Therapy for BBS

Professor Phil Beales, UCL and Axovia Therapeutics

Professor Phil Beales gave an important update on the world's first gene therapy developed specifically for Bardet-Biedl Syndrome (BBS). The treatment, called AXV-101, is designed to preserve sight in people with BBS1.

Professor Beales explained that this therapy doesn't fix the faulty genes and is not expected to restore lost vision. Instead, it works by adding a new, healthy copy of the BBS1 gene into the eye, to slow down further damage and to preserve remaining vision.

The team hopes to begin the trial in autumn/winter 2025, depending on regulatory approval. Updates on the progress of the trials will be posted on the BBS UK website.



Therapeutic Approaches for Retinal Dystrophies

Robert Henderson, Consultant Ophthalmologist, Great Ormond Street Hospital

Robert spoke about how retinal dystrophies, including those caused by Bardet-Biedl syndrome (BBS), are diagnosed and monitored, and how they may be treated in the future.

Gene Therapy and What It Can Do

Robert gave a brief introduction into how the eye works before giving an overview of gene therapy, sharing an example of an existing treatment for a different genetic eye condition caused by faults in the RPE65 gene.

He explained that a harmless virus is used to deliver a working copy of the gene directly into the retina. The goal is to help surviving cells function better and slow further vision loss.

Robert showed powerful before-and-after footage of a young boy who, before treatment, struggled to move around, even in good lighting. After gene therapy, the boy could confidently pick up small beads from the floor. It was a reminder of the potential impact these treatments can have, even if the results vary from person to person.

While this particular therapy isn’t for BBS, it shows what is possible, and helps lay the groundwork for future gene therapies targeted specifically at BBS genes.

Why BBS Gene Therapy Is More Complex

Not all genes can be treated the same way. Current gene therapy methods only work for smaller genes, and many BBS-related genes are quite large. This presents a challenge, but researchers are already testing ways to split big genes into two parts and deliver them separately.

He mentioned that trials for split-gene approaches (like those for Usher syndrome) are just beginning. If successful, this technique could one day be used for BBS genes too.

Other Future Treatments: Beyond Gene Therapy

Robert went on to discuss several promising areas of research for people who have already lost most, or all of their vision:

- **Optogenetics:** This uses light-sensitive proteins (borrowed from organisms like algae) to help other cells in the eye respond to light. People receiving this treatment would need to wear special goggles, but the early results are encouraging.
- **Stem cell therapy:** Researchers are working on growing “mini-eyes” in the lab using stem cells, then printing sheets of photoreceptor cells and implanting them into the retina. This is still early-stage, but it could one day help restore vision where none remains.

Robert cautioned families to be careful about overseas clinics or treatments promising miracle cures. Often, these are not based on sound science and some have caused serious harm.

Final Thoughts

Robert closed by reminding families that we are in an exciting time of progress. Many of these treatments are still in trials, and results may take time, but the field is moving fast. Even in the past decade, advances in testing, imaging, and therapy have changed what's possible, and more options are on the horizon.

> **"This work gives us real hope for preserving vision, and one day, maybe even restoring it."**

Setmelanotide, the BBS Registry & Sleep Study

Dr Elizabeth Forsythe, Consultant in Clinical Genetics

Dr Elizabeth Forsythe gave a wide-ranging update on three important areas of work happening across the national BBS clinics: the launch of Setmelanotide clinics, the development of the UK BBS Registry, and the start of a new study into sleep problems in children with BBS.

Setmelanotide Clinics: A New Option for Managing Hunger and Weight

Setmelanotide is a new medication approved in the UK in May 2024 for managing weight and excessive hunger (hyperphagia) in children with Bardet-Biedl syndrome. While not suitable for everyone, it represents a major step forward in offering new support to families.

Dr Forsythe explained that:

- The drug is only approved for children, not adults (yet).
- To be eligible, a child must:
    - Have a genetic diagnosis of BBS.
    - Struggle to maintain a healthy weight (based on BMI).
    - Experience excessive hunger, confirmed via a structured questionnaire.
    - Be medically safe to start treatment.

Setmelanotide is delivered as a daily injection under the skin, typically in the tummy. Side effects are usually mild and similar to other weight-loss drugs, including temporary nausea or tummy upset. A unique side effect of Setmelanotide is that skin tone may darken, however this is reversible if treatment stops.

Eligible families are seen in one of two national clinics, Great Ormond Street Hospital (GOSH) or Birmingham Children's Hospital. Children need to attend two appointments:

1. An initial consultation and eligibility assessment.
2. A start-of-treatment session where families learn how to give the injections, supported by a nurse and a homecare team.

It's important to note that Setmelanotide can only be prescribed through a shared care agreement with a child's main doctor (either their GP or paediatrician). These doctors will be asked to help monitor the child's health more closely, especially at the beginning.

Importantly, Dr Forsythe reminded families that while Setmelanotide is a useful tool to aid weight loss, it isn't a replacement for healthy eating, regular movement, and emotional support. These things remain essential whether a child is taking the medication or not.

Dr Forsythe encouraged families not eligible for Setmelanotide to remain hopeful, as other promising weight-loss drugs are emerging, particularly for adults, and may become available for people with BBS in the future.

The BBS Registry: Learning From the Whole Community

The UK BBS Registry is a secure national database that gathers anonymised clinical information from all four specialist BBS clinics. Dr Forsythe explained that the registry is essential for:

- Spotting patterns in how BBS presents and changes over time.
- Improving services, so care is consistent across centres.
- Preparing for future treatments and research trials.

The data collected includes basic identifiers (like age and genetics), along with health information from regular clinic visits, including eye and kidney test results, hormone levels, developmental milestones, and medications. Nothing outside of the clinic assessment is added.

Taking part is optional, and families can ask questions or opt out at any time.

The registry allows doctors to move from treating individual cases to seeing the bigger picture, helping the whole BBS community by sharing knowledge, improving care, and supporting research.

Sleep in BBS

Sleep, and obstructive sleep apnoea, is a topic that hasn't been widely explored in BBS, but Dr Forsythe believes it deserves more attention.

Obstructive sleep apnoea is a condition where breathing pauses or becomes shallow during sleep due to blocked airways. It is more common in children with obesity, large tonsils, or smaller jaw structures, all of which can feature in BBS.

Obstructive sleep apnoea can lead to daytime sleepiness, difficulty concentrating, behaviour or learning challenges, and long-term heart and blood pressure problems.

Some common signs to look out for include:

- Loud snoring
- Gasping or choking sounds during sleep
- Restless sleep
- Feeling unusually tired during the day

Dr Forsythe encouraged families who recognise these signs to speak to their child's doctor, as obstructive sleep apnoea is treatable and can greatly improve quality of life.

To help gather more data, Dr Forsythe's team have created a short sleep questionnaire. Families attending the conference were invited to fill it in to help researchers learn more about sleep problems in children with BBS.

Final Messages

Dr Forsythe closed by emphasising the value of community involvement in all three areas she discussed. She thanked families who have already shared information for the registry or supported the new sleep study.

> **"Everything we learn, from one person or a hundred, helps us move forward in understanding BBS and supporting families better."**

Question & Answer Session

Prof Phil Beales, Dr Elizabeth Forsythe and Robert Henderson

Topics covered: Sinus issues, sleep concerns, gene therapy trials, and future treatment options

Q: Are sinus problems like chronic rhinitis common in people with BBS1?

Dr Elizabeth Forsythe: Chronic rhinitis isn't commonly reported in BBS, but people with BBS are more prone to recurrent chest infections, due to cilia not functioning properly in the lungs.

Prof Phil Beales: We also frequently see glue ear in children with BBS for similar reasons - poor cilia function leading to fluid build-up. However, chronic rhinitis isn't something we've seen often in the BBS population. These symptoms should be managed by an ENT (ear, nose, and throat) specialist. Home sinus rinses can help, but seeing a specialist can offer better options, including procedures that improve drainage.

Q: My son snores very loudly and often chokes in his sleep. What can I do?

Dr Elizabeth Forsythe: This sounds like sleep apnoea, which is common in people with BBS. Going to a sleep clinic is the right next step. They can perform a sleep study to diagnose the severity and recommend treatment.

Q: Could snoring and choking cause serious issues like heart problems?

Dr Elizabeth Forsythe: Yes, severe untreated sleep apnoea can increase the risk of other health problems, including cardiovascular issues. Weight loss can help, but professional assessment is vital.

Q: If I live alone, how would I know if I have sleep apnoea?

Dr Elizabeth Forsythe: It is usually noticed by others, partners, family members, or housemates however, if you feel excessively sleepy during the day or struggle to concentrate, that could also be a sign that you may have sleep apnoea.

Q: What's the timeline for the gene therapy trial?

Prof Phil Beales: We are waiting for final MHRA regulatory approval. Once we have that in place, we can start inviting eligible participants in stages.

Q: What happens in the mice treated with gene therapy?

Prof Phil Beales: In BBS1 mice, the untreated eye degenerates normally, while the treated eye maintains vision. This shows promise for preserving sight if treated early.

Q: Will gene therapy be developed for other BBS genes like BBS10?

Prof Phil Beales: A potential BBS10 gene therapy is being explored by colleagues in the US, though it faces funding and regulatory challenges.

Robert Henderson: Trials are expensive - £10 million or more. A proposed 'compassionate use' treatment at Great Ormond Street was not approved. Future progress depends on investment and regulatory backing.

Dr Elizabeth Forsythe: We are hopeful the process for ultra-rare conditions will get easier over time, especially with technological advances.

Q: How will participants be selected for the BBS1 gene therapy trial?

Prof Phil Beales: The trial is open to anyone in the UK and Ireland attending BBS clinics, who meets eligibility criteria. The process will be phased, fair, and robust.

Robert Henderson: Selection will depend partly on retinal condition - there needs to be enough preserved vision for the treatment to work. Screening will assess each case individually.

Q: Why is the current BBS1 gene therapy trial only open to ages 4–17?

Prof Phil Beales: The goal is to treat patients early on, while there is still functional vision to preserve. Later trials (phase 3) will likely include older age groups once safety and effectiveness are proven.

Robert Henderson: Early-stage trials aim to measure results quickly, so researchers target those at the point of most rapid vision decline.

Q: Is there hope for people who've already lost significant vision?

Robert Henderson: Yes, but it will likely require combination treatments, gene therapy, stem cell therapy, and technological solutions like optogenetics or even artificial vision.

Devices like the Argus retinal chip allow people with no vision to detect edges and navigate spaces. While not full vision, these synthetic aids can significantly improve independence.

Planning for the Future: Wills, Trusts and Decision-Making

Philip Warford, Renaissance Legal

Philip Warford's presentation was about how families can plan to protect the long-term wellbeing and financial security of someone with Bardet-Biedl syndrome (BBS). He highlighted the risks of leaving money without safeguards, explained the different legal tools available, and stressed the importance of planning while individuals still have capacity.

Why future planning matters

Leaving money or assets directly to a person with a rare complex condition, including BBS, can have unintended consequences. It may:

- Put them at risk of financial abuse.
- Affect their entitlement to means-tested benefits.
- Leave funds vulnerable if they (or someone holding money for them) experience divorce, bankruptcy or other financial difficulties.

Philip explained that these problems can be avoided with careful planning, using tools such as Trusts, Wills and Powers of Attorney. This creates security, flexibility and peace of mind for the whole family.

Using Trusts to protect assets

A Trust is a legal arrangement that allows assets to be managed by appointed trustees for the benefit of someone else:

- Discretionary Trusts: Gives trustees the flexibility to decide how and when funds are used. This is useful where needs may change over time.
- Disabled/Vulnerable Person's Trusts: Designed for those who meet the legal definition of disability (often linked to receiving benefits such as DLA, PIP or Attendance Allowance). These Trusts can receive special tax treatment.

The right Trust depends on:

- The beneficiary's needs.
- The level of flexibility required.
- The type and value of assets involved.

Philip stressed that trusts should be tailored to each family's situation and drafted by solicitors with experience in disability planning.

Wills: Still important, but not enough on their own

A Will is essential for setting out who inherits your estate. However:

- Leaving assets outright to a vulnerable person can still cause the issues outlined above.

- The safest approach is to direct funds into a suitable Trust via the Will.
- A Letter of Wishes can be included, to guide trustees on how you'd like funds to be used.

Decision-making and mental capacity

The Mental Capacity Act 2005 sets out the framework for supporting decision-making:

- Always presume a person has capacity unless it is proven otherwise.
- Support the individual to make their own decisions wherever possible, for example, by using accessible formats or choosing a better time of day to talk.
- Capacity can vary, for example, over time and according to the complexity of the decision.

If a person has capacity, they can make a Lasting Power of Attorney (LPA):

- Property and Financial Affairs LPA - covers money, banking and property.
- Health and Welfare LPA - covers medical treatment, care and living arrangements.

These LPAs allow trusted people to make decisions on behalf of someone, if capacity is lost in the future.

Court of Protection

Where no LPA is in place and the person lacks capacity, the Court of Protection can appoint a Deputy:

- Property and Affairs Deputy - responsible for managing someone's financial affairs.
- Personal Welfare Deputy – authorised to make major health or care decisions on someone's behalf (less common).

Deputyship applications can be expensive and time-consuming, so advance planning with LPAs and Trusts is preferable.

Philip's practical recommendations

- Seek legal advice from specialists familiar with planning for disabled or vulnerable people.
- Combine a Will with the right Trust and LPAs for a layered approach to protection.
- Keep plans under review - benefits rules and laws can change.
- Use a Letter of Wishes to help trustees understand your intentions.

Renaissance Legal provide free guides on Trusts, LPAs, deputyship and decision-making via their website. They encourage families to start these conversations early to give everyone confidence about the future.

www.renaissancelegal.co.uk/

Stefan Crocker: Personal Perspective

Stefan Crocker shared what it's like living with BBS, navigating the world with a visual impairment, and staying active, connected, and independent - delivered with his signature sense of humour and openness.

Stefan, now 43, was diagnosed with BBS in 2003 after a visit to Moorfields Eye Hospital. At the time, he was exploring laser eye surgery for astigmatism, but tests revealed a more complex picture. Since then, he's been closely involved with BBS UK, first as a conference attendee, then as a trustee, chair, vice chair, and now as a dedicated volunteer.

Building Confidence, One Journey at a Time

While Stefan now travels widely, both in the UK and abroad, he didn't always feel comfortable doing so. Early on, even a short train journey was daunting. He described how he slowly built confidence by starting small, going from St Albans to London, and gradually worked up to multi-leg journeys involving buses, trains, tubes, and now, even international flights.

Stefan's message was clear: it's all about small steps. If you're nervous about travelling independently, start with a short route. Even walking to a new bus stop can feel like a big win, and it all adds up.

> **"Everything is an achievement. You just build and build, and suddenly you're booking a flight to America."**

Travel Tips and Real-Life Hacks

Stefan gave practical advice for others with BBS thinking about travelling:

- Use the Passenger Assistance App to request help at UK train stations.
- Be clear and proactive with communication; tell staff where you're going and what you need.
- Expect that things may not always go to plan, but there are usually people willing to help.

Stefan also uses tools like Moovit for bus times, and Apple AirTags on his luggage for peace of mind. Bright straps and photos of his bags also make it easier for airport staff to locate his luggage.

In the US, Stefan made connections via Facebook before attending the US BBS conference, which helped with on-the-ground support. He recommended using a local travel agent for a more personalised service, especially when booking flights with accessibility needs.

Tech That Makes Life Easier

Stefan uses a range of technology to support independence:

- Seeing AI helps to identify items in shops when staff aren't available or helpful.
- Uber enables accessibility needs to be directly relayed to drivers.
- Messaging apps and Zoom social groups support connection with the BBS community, although Stefan is also a fan of old-school phone calls with his friends.

Staying Active and Giving Back

Stefan is a volunteer for BBS UK and is a member of his local Sight Loss Council in Bedfordshire, where he works to improve services for others. Volunteering is important to him. He said it's a way to give back, share lessons learned, and see others grow from advice and encouragement.

Stefan enjoys playing visually impaired tennis, politics, walking, and meeting up with friends across the country.

A Message to Others

Stefan closed with an encouraging reminder:

"You don't have to leap into solo international travel right away. Just pushing your boundaries, a little at a time is enough. Start with something small. Once you do, you'll be amazed how far you can go."

Support Available: For those who would like to travel more independently, having the right skills and confidence is key to staying safe. If you'd like to build your travel skills and confidence, BBS UK can help you to access local cane training or travel training. For support, email rebecca.perfect@bbsuk.org.uk.

Staying Safe Online

Sophie Corness, Royal National College for the Blind

Sophie Corness gave a helpful talk about online safety. With more of our lives happening digitally, from shopping and banking to friendships and dating, it's important for everyone to know how to protect themselves online.

Sophie shared personal stories, practical advice, and real-world examples of scams, stressing that anyone can be targeted, and it's nothing to be embarrassed about.

Key Online Risks and How to Spot Them

Sophie explained some of the most common online threats:

- **Scam emails and fake websites** often pretend to be from trusted companies. Look out for bad spelling, suspicious sender addresses and urgent messages that pressure you to act quickly.
- **Malware** (malicious software) can be spread by clicking on untrustworthy links. Always pause before clicking on something unexpected, even if it looks official.
- **Identity theft** happens when fraudsters collect personal details to impersonate you. Avoid posting too much personal information on public profiles.

If something seems too good to be true, it probably is, especially time-limited offers on social media.

Simple Ways to Stay Safe

Some of Sophie's top tips included:

- Use strong, unique passwords - don't reuse the same one for multiple sites. Consider using a password manager to store your passwords securely. Most devices have password managers built in.
- Turn on two-factor authentication wherever possible. This extra step, for example, receiving a code by text, adds another layer of protection.
- Keep your devices and software updated to block security threats.
- When shopping online, check the site information to confirm if the site is secure. A padlock symbol will be visible next to the URL. You can use a screen reader to navigate to this information.

Sophie also warned against using public Wi-Fi for sensitive tasks like banking. If you must use it, avoid entering personal or payment information, and turn off file sharing or auto-connect features.

Privacy and Social Media

With over 56 million social media users in the UK, Sophie reminded everyone to think before they post. Social media profiles can unintentionally give away bits of personal data that, when pieced together, become valuable to criminals.

It's especially important to:

- Check privacy settings on every platform to control who sees what.
- Avoid sharing information like your school, workplace, birthday, or home location publicly.
- Be cautious about sharing photos, strong opinions, or personal updates, particularly if you're tired, upset, or reacting emotionally.

Sophie also touched on cyberbullying, explaining that online bullying is similar to traditional bullying but often harder to escape. If it happens, don't hesitate to block the person, report them, and seek support. You don't have to tolerate abusive behaviour online.

Dating and Online Friendships

Online dating and friendships are common and often positive, but they carry risks. Sophie advised:

- If you decide to meet up, make sure the first time is in a public place.
- Tell someone you trust where you are going and who you are meeting.
- Be honest in your self-descriptions.
- Remember, not everyone is who they say they are online - stay cautious until trust is built.

RNIB Support for Online Safety

Sophie shared additional resources from the Royal National Institute of Blind People (RNIB) to help people with sight loss stay safe and confident online. Their support includes:

- Advice on privacy settings, strong passwords, and avoiding scams.
- Assistive tech support, including help using screen readers and accessibility tools on social media.
- Help through their Technology for Life team and helpline: 0303 123 9999

For more information go to www.rnib.org.uk

Final Thoughts

Sophie closed by reminding us that online safety isn't something you do once, it's an ongoing process. Technology changes fast, and criminals are constantly finding new tricks. The best defence is staying informed, cautious, and never afraid to ask for help.

> **"It's not about being scared, it's about being smart."**

BBS UK Update on Services

Tonia Hymers, Operations Manager

The Conference opened with a moment of remembrance for two much-loved members of the BBS UK community, Julian Thomas and Jackie Farrington. Both regular attendees and former trustees, they are remembered for their humour, warmth, and kindness.

Tonia reflected on the joy of being back together as a community and thanked everyone who has supported BBS UK over the past year through fundraising, volunteering, donations, feedback, or encouragement, noting that supporters are "at the heart of what we do."

Community Impact and Strategy

BBS UK's vision is to ensure that everyone accessing its services is supported, connected, informed, and empowered. A recent community audit showed:

- 91% trust the charity and feel comfortable reaching out
- 80% found services helpful
- 82% felt more aware of support available
- 74% felt more confident managing the condition

The results of the community audit are guiding the development of a new three-year strategy, to be shared with the community soon.

Services Update

Advice Service: With local support under pressure, the Advice Service has become a vital safety net, helping families secure support and services across education, transport, housing, social care, and welfare. Demand has increased in complexity and intensity, prompting expansion of the Advice Team, funded by a legacy gift from Jackie Farrington. Since April, two new Advice Workers, Beatrice Adeogun and Alis Stevens, have joined, bringing expertise in social care and education.

BBS Clinics: Partnering closely with NHS specialist clinics, BBS UK provides support from diagnosis through every stage of the patient journey. Over the past year, BBS UK:

- supported more than 400 patients to attend over 60 clinics
- logged approximately 3,000 contacts
- Managed a database with over 700 patients and 1500+ entries

Other Services:

- Mental health support is being piloted with Rareminds, funded by the National Lottery.
- The IT Equipment Fund provides devices to reduce isolation
- The Chris Humphreys Memorial Fund has supported 20 first-time attendees to attend a BBS UK Conference.

Research and Collaboration: While BBS UK does not directly fund research, it contributes to protocols, funding applications, NICE appraisals, and disseminates information. Participation on external boards, and other collaborations, enhance understanding of the research landscape and broader BBS community.

Funding and the Future: Despite a small team of (at the time of presenting) seven part-time staff, BBS UK has achieved significant impact. Funding from Jackie Farrington's legacy (Advice Service, three years) and BBC Children in Need (core salaries, three years) allows longer-term planning. Spreading the funding maximises the impact of the legacy, but additional community fundraising, corporate support, and regular giving are essential to sustain services across the next few years and beyond.

How You Can Help: Last year, supporters raised over £17,500; this year's target is £20,000:

- Friends of BBS UK: Monthly donations, even £5, provide a stable income stream
- One-off donations: This year's target is £6,000
- Fundraising events: From marathons to bake sales, every effort counts
- Corporate giving: Matched donations or sponsorship can amplify support
- In-memory and legacy giving: Create a lasting impact

Final Thoughts

Tonia closed by emphasising that everything BBS UK does is about helping people with BBS live better, more connected lives.

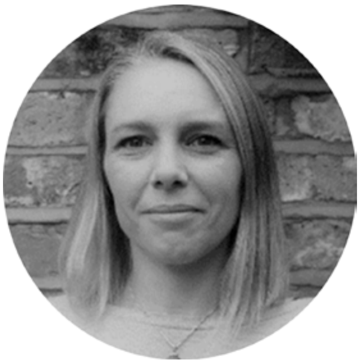
> **"We are stronger when we work together, fundraise together, advocate together, and share experiences that build understanding and drive change. We are stronger when we are not afraid to ask for help, or to offer it."**

Support BBS UK at: www.bbsuk.org.uk/support-us

Thinking About Food

Kenneth Michie, Dietitian, St Thomas' Hospital

Dr Emma McGibbon, Clinical Psychologist, St Thomas' Hospital



The aim of this session was to explore the many reasons why we eat, particularly for people living with BBS, and to offer practical strategies to better understand and manage food choices, hunger, and emotional triggers.

Understanding Obesity and Hyperphagia

Kenneth introduced a systems model of obesity, showing how various factors interact:

- Food environment: Cheap, high-calorie foods are everywhere.
- Societal and emotional influences: Stress, pressure, and emotions often lead to comfort eating.
- Activity levels: Inactive lifestyles and limited access to exercise facilities are common, especially for people with visual impairment.
- Biological factors: Age, sex, metabolism, and especially genetic conditions like BBS, influence weight and hunger.

Patients with BBS may have some form of hyperphagia, an abnormally strong and persistent hunger, which for some, can have a big impact on their life and wellbeing. Hyperphagia is thought to be caused by an imbalance in hormones, particularly gut hormones that promote hunger and satiety. Obesity due to hyperphagia is treated with dietary management, increased exercise, and more recently, with drug therapies coming to market, including Wegovy, or Setmelanotide.

Managing Hunger and Making Food Choices

Practical tips shared during the session included:

- High-protein meals help you feel fuller for longer.
- Fibre-rich foods (like fruits, vegetables, and whole grains) support satisfaction and fullness.
- Reducing sugary and processed carbs can prevent blood sugar spikes that trigger hunger.
- Stick to regular mealtimes to reduce constant snacking.
- Stay hydrated—sometimes thirst can feel like hunger.

Kenneth also emphasised the importance of recognising that small daily choices, not the occasional treat, are what contribute to long-term weight gain.

Real-Life Strategies from the BBS Community:

- Batch cooking meals and freezing portions to avoid overeating.
- Buying snacks individually instead of in bulk.
- Measuring portion sizes to stay aware of how much is being eaten.
- Planning meals and snacks ahead of time.
- Avoiding shopping when hungry to prevent impulse buys.
- Choosing low-calorie drink alternatives.
- Setting goals to stay motivated.

Why Do We Eat? Emotional and Environmental Triggers

Emma focused on understanding why we eat, not just what we eat. While physical hunger is a genuine need, many of us also eat in response to:

- Environmental cues, for example, mealtimes, social settings, or visual triggers.
- Emotional cues, for example, feeling bored, sad, lonely, or even happy.

Emma encouraged participants to reflect on their eating triggers and understand the difference between physical and emotional hunger. Being more aware of when, where, and why we eat can help people make more mindful decisions.

Mindful vs. Mindless Eating

- Mindless eating often happens when we're distracted, bored, or not paying attention. It can lead to overeating and less satisfaction.
- Mindful eating means slowing down, being present, and enjoying the food, leading to better portion control and awareness of hunger cues.

Because people with BBS may not always receive reliable hunger/fullness signals from their body, planning meals in advance becomes especially important.

Emma led the attendees to try mindful eating by taking a segment of orange and taking the time to eat it slowly, appreciating the smell, taste and texture of it.

Final Takeaway

Understanding hunger, recognising triggers, and planning ahead, can empower people with BBS to feel more in control of their eating. As both Kenneth and Emma made clear, it's not about perfection or restriction, it's about making informed, sustainable choices that support health and wellbeing.

Retina UK's Support Services

Paula McGrath, Deputy Chief Executive

Mark Baxter, Information and Support Coordinator

Retina UK supports people with inherited progressive sight loss, including those living with BBS. While the Charity funds research, much of their work centres on making sure people don't face sight loss alone.

Paula and Mark highlighted that engaging with Retina UK's services can reduce feelings of loneliness, isolation, and depression.

Ways to Connect and Get Support:

- Talk and Support Service: A telephone befriending scheme matching individuals with volunteers who also live with inherited sight loss.
- Local Peer Support Groups: In-person meet-ups across the UK, which can include coffee mornings, theatre trips, museum visits, or social outings.
- Online Peer Support Groups: For those without a local group or who prefer virtual meetings. Options include:
  - National Peer Support Group
  - 'Talking' series groups: Talking Tech, Talking Travel, Talking Creative Arts, Talking Home & Garden
  - Men's, Women's, and Young Adults (18–30) groups
- Young Adults Group – Support for those navigating university, employment, housing, or early diagnosis. Includes an active WhatsApp community.

Retina UK also offers:

- Discover Well-being: A free online course with practical tools for managing the emotional impact of sight loss.
- Helpline: Trained staff and volunteers providing both practical advice and emotional support.

The Charity runs an annual conference, with research updates, presentations, and the chance to meet others with sight loss. It is also streamed online.

People can also stay informed through newsletters, webinars, podcasts, magazines, and the charity's Sight Loss Survey, which helps shape future services. Visit the Retina UK website for more information. www.retinauk.org.uk

Communication at a Cellular Level

Dr Emilia Kieckhöfer and Julia Günzler, Cologne, Germany

Jannis von Spreckelsen and Dr Viola Kretschmer, Mainz, Germany

Emilia, Julia, Jannis and Viola, all current or former members of Professor Helen May-Simera's research team, were tasked with delivering a tactile, hands-on science session designed to be accessible for everyone.

The weekend also included informal opportunities to connect with the research team, such as the Friday and Saturday evening “Meet the Researchers” sessions. Here, children could get hands-on with scientific instruments, including pipettes, sparking curiosity and interest in science.

Thank you once again for joining us for the weekend and taking part in the family conference events, including this interactive science session.

Emily Bartell: Personal Perspective

Emily Bartell travelled from her home in North Carolina, USA, to share her personal journey of living with Bardet-Biedl syndrome (BBS). Her story was honest, reflective, and at times emotional, offering insight into the challenges and growth that come with progressive sight loss and learning to live independently.

A Life of Learning and Relearning

Emily was diagnosed with BBS in the early 1990s by chance, through a well-timed referral, and a doctor who had just read an article about the Syndrome. At the time, she was also misdiagnosed with Retinitis Pigmentosa (RP), a mistake she only learned about years later. She explained how diagnosis in the US at the time, especially in a more rural area, was often hit-or-miss, especially when genetic testing was still limited.

Emily didn’t start experiencing major effects from BBS until about 10 years ago. Her upbringing was largely typical; she did everything her siblings did and grew up in a sighted world, with little connection to others who were visually impaired.

But as her sight declined, daily tasks became more difficult. She described how hard it was to ask for help, something she still works on, and how the loss of independence can be deeply frustrating, yet she’s committed to adapting. She began learning cane skills and prepared herself to travel solo, including for this trip to the UK.

Travelling Alone, Learning About Herself

Emily’s trip to the UK was as much about personal growth as it was about attending the Conference. She made a conscious decision to travel alone, without her partner, knowing that being accompanied by someone sighted, might make it harder for her to push herself.

Emily had arranged to explore some of the UK before attending Conference, and on arriving in Edinburgh, she realised that she had far less usable sight than she thought, and she had been relying on memory to navigate. But instead of falling apart, she chose to see it as a turning point, and that moment forced her to build her cane skills, and practice asking for help; Emily described it as a powerful step forward in her independence.

Building Her Skills, Reclaiming Her Identity

Emily explained that losing sight was a kind of identity shift, but also an opportunity. Emily shared how, when she could no longer kayak, she took up horse riding and discovered a new passion. When transport became a challenge, she and her partner bought a tandem bike. She learned Braille over the phone with a teacher who left lesson materials on her door, starting with a muffin tin and ping pong balls to understand Braille dots by touch.

Emily swims, hikes, plays guitar, and makes ceramics, something she pursued through a Bachelor of Arts in Ceramics. Her degree in massage therapy, focused on neuromuscular work, also revealed unexpected strengths. Because she couldn’t rely on vision, she had a better ‘feel’ than many of her sighted classmates.

The Importance of Support and Perspective

Emily emphasised that success depends on having a support network, whether that’s family, friends, or online communities. She didn’t grow up with Facebook groups or BBS-specific support, so much of what she learned, she had to figure out for herself.

She urged others living with BBS to try to reframe their challenges as strengths, not in a forced ‘positive thinking’ way, but through practical reflection. For example, her vision loss gave her access to new skills, insights, and relationships she might never have developed otherwise, she said, “we all have limitations... but sometimes those limits open new doors.”

Emily also stressed the emotional weight of progressive sight loss, how it can feel like a grieving process every time vision worsens. Still, she sees her life as full and evolving.

Why She Came

Emily came to the BBS UK Conference not just for the presentations, but to reconnect with parts of herself she felt she had lost. She described finding joy in talking to strangers, navigating trains independently, and feeling part of a community where she didn’t have to explain everything.

For Emily, networking is her superpower, and she invited anyone at the conference to come say hello.

Team BBS UK would like to thank Emily for travelling so far to attend the conference, and for sharing her story with the community.

Supporting Transition to Adulthood

Anna Smith, Child and Adolescent Psychotherapist, Rareminds

Marie McGee, Transition Care Coordinator, Birmingham Children's Hospital

The aim of this joint session was to explore how parents can best support young people with BBS, as they prepare for the changes of adolescence and adulthood. The session opened with a short animation introducing T-KASH, Transition – Knowledge and Skills in Healthcare), a set of free resources created by young people from the Alström Syndrome UK Hear My Voice Youth Forum. These tools were designed to help young people, families, and professionals understand what transition in healthcare means and how to prepare for it.

The T-KASH framework, which was used in the development of BBS UK's 'My Life, My Future' handbook for young people, covers many areas of life, such as relationships with family, personal interests, staying safe, emotions, and managing medical care. It also highlights practical life skills like opening a bank account, handling money, and preparing for adult healthcare services. These resources are designed to be used in hospitals, schools, GP practices, and at home.

Anna and Marie explained that transition is something that happens over time, not in one big moment. It's the gradual journey a child or teenager makes as they learn new skills and take on more responsibility for their health and future. They said it is best to start talking about transition early, so it becomes a normal part of growing up. The sooner it's introduced, the less scary it becomes.

Each young person will take a different path. Some may be ready to take on more responsibility quickly; others will take much longer, and that's perfectly okay. Families should move at their child's pace, adjusting plans to fit their child's understanding, not just their age.

Supporting Young People Through Change

The speakers explained that teenagers face unique challenges when it comes to transition. Their brains are still developing, particularly the parts that manage planning and decision-making. On top of that, young people with BBS may also be managing vision loss, learning disabilities, autism, or other complex needs. This means their emotional readiness for transition may not match their actual age. Parents and carers should focus on what the young person is ready for, not what the calendar says they 'should' be doing.

Anna shared some helpful ideas for parents:

- Try to have conversations while doing something side by side, like driving, walking, or playing a game, instead of having intense face-to-face talks.

- Listen to your child's worries without judgement. Let them know it's okay to feel nervous or unsure.
- Encourage small steps. A young person doesn't have to take control of everything at once - just asking a question in a clinic or helping track an appointment can be a positive start.
- Support them to learn how to speak up about their needs in a way that works for them.

The speakers recommended the Cerebra Transition Guide for families whose children find hospital visits stressful. This free resource offers practical tips for building positive relationships with healthcare staff and helping young people feel more confident in medical settings.

BBS UK Patient Liaison Officers recommend NHS guidance available via the Great Ormond Street Hospital website, 'Helping your Teenager Cope with Hospital'. They also invite parents to contact them if support is needed, so they can ensure the visit is adapted to meet the needs of the young person, to make it as stress-free as possible.

Progress might not always be steady, there will be ups and downs, and times when a young person seems to take a step backward. This is all part of the process.

Making Transition Feel Normal

When we talk about transition regularly and early, it becomes a normal part of growing up.

Anna suggested that parents start mentioning future changes from a young age. For example, a parent might say, "When you're older, you might have a different doctor," or "When you're grown up, your appointments might be at a different hospital."

Schools also play a part. During the Year 9 EHCP review, young people start thinking about adulthood. This is a natural time to introduce conversations about healthcare transition too.

Most importantly, families should try to plan transition when things are calm. After a hospital stay or a medical crisis is not the best time to make big changes, because stress makes it harder to think clearly.

The session closed with three key points for families to remember:

- Transition is a process, not an event. It takes time, reflection, and practice.
- Every young person is different. Some may need more time, others less, and both are okay.
- Start early. Early, gentle conversations make future changes easier to manage.

Anna and Marie encouraged families to trust their instincts, move at their child's pace, and seek help when needed.

The 'My Life, My Future' booklet is a young person's guide to living their life with Bardet-Biedl syndrome. The booklet has been put together by BBS UK to help young people who have BBS achieve the best life possible.

Cognitive, Behavioural and Social Presentations in Children with BBS

Dr Gabrielle Blumer, University of Surrey

Dr Gabrielle Blumer presented the results of a collaborative research project carried out with Dr Emma McGibbon, Great Ormond Street Hospital, and Dr Jo Moss, University of Surrey, with the support of BBS UK and many participating families.

The aim of the research was to better understand how Bardet-Biedl syndrome affects learning, behaviour, social communication, and emotional wellbeing in children and young people. This includes looking at areas of strength as well as any areas of difficulty, where extra support might be useful.

Intellectual disabilities or learning disabilities are common in people with BBS. This affects the way that somebody learns, remembers, or applies information. It is important to note that learning disabilities are different for everyone. People with a learning disability may need varying levels of support, from occasional help with complex tasks, to daily assistance with self-care, cooking, and social activities.

Research shows that people with BBS often experience social communication differences, affecting both verbal and non-verbal interaction. These are traits also seen in autism, and individuals with BBS are more likely to be diagnosed with autism or display autism-like behaviours.

Results of the studies

The team's research included two studies. One involved direct assessments of children's learning and daily living skills, and the other gathered information from families using questionnaires about social, emotional, and behavioural challenges. The study showed:

- In a group of 21 children and young people with BBS, 43% met the criteria for a learning disability, though none had been assessed or diagnosed before this study.
- Of those who did not meet the full criteria for a learning disability, many scored below the expected range for their age, meaning that most children with BBS would benefit from learning support.
- Some children showed strengths in non-verbal problem-solving, for example tasks involving puzzles and pictures.
- Processing speed was often slower, even among those with higher cognition, meaning extra time for learning tasks is likely to help many of those with BBS.
- Children's practical skills for daily life were below average, including dressing, organising, and social independence.
- A larger questionnaire study found 80% of children with BBS showed social

communication differences, similar to what is seen in autism. Half were in the highest range suggesting significant differences in their social communication.

- Half of the children in the study showed clinically significant emotional and behavioural difficulties, and another quarter were in the borderline range.
- Emotional difficulties including anxiety or sadness were more common than disruptive behaviours.
- A lower quality of life was reported, especially in areas related to physical health.
- Family quality of life was also impacted, but family relationships were reported as a strength, suggesting that strong family support can protect against some of the emotional challenges children face.
- Emotional and social difficulties had a greater impact on children's and families' well-being than physical health issues, including vision loss or hyperphagia.
- Children with BBS were often described by their families as happy, friendly and fun to be around.

What Does This Mean for Families?

Dr Blumer explained that these findings highlight the need for routine developmental assessments, to look beyond physical health and identify learning, social, and emotional needs early on. These assessments can:

- Help secure appropriate support in school (for example, through an EHCP)
- Give families a clearer understanding of their child's strengths and challenges
- Guide practical support in daily life

Dr Blumer warned about 'diagnostic overshadowing', where health professionals might wrongly assume all a child's challenges are simply part of BBS, and miss other diagnoses like autism, ADHD, or anxiety. Families should feel confident to ask questions and request assessments if something doesn't feel right.

What Should Parents Do if They Have Concerns?

Early assessments could help families and schools better understand and support their child's needs, however, at present, there is no national service in the UK routinely assessing children with BBS for learning or social difficulties. Dr Blumer encouraged families to trust their instincts and seek assessments if they feel something is being overlooked, in the first instance they should speak to:

- Their GP, who can refer for neurodevelopmental assessments
- The SENCo at their child's school
- The psychologist in the BBS clinic

Dr Blumer and the team thanked all the children, young people, and families who took part in the research. Without their time and openness, this work wouldn't have been possible. They encouraged others to consider taking part in future studies, as sharing lived experiences is key to improving understanding, support, and services for all those living with BBS.

Habilitation for Children: What to expect from your child's mobility and independence

Suzy McDonald, HabVIUK (the national body for habilitation specialists)

Suzy McDonald is a habilitation specialist from Priestley Smith Specialist School in Birmingham. She spoke about the importance of habilitation for children with a vision impairment, how it supports a child's development, and what parents should expect from a habilitation programme.

What Is Habilitation?

Habilitation means teaching children with vision impairments how to move around safely and live as independently as possible. It combines mobility training, including learning to use a cane or travel independently, with practical life skills, for example, making a snack or getting dressed. Habilitation also supports emotional wellbeing, self-determination and social inclusion; the aim is for children to develop confidence and independence, helping them to succeed in school and in life.

How Support Is Tailored

Every child is different, and their habilitation programme will depend on

- Age and stage of development
- How much vision they have and whether this might change
- Other support needs (physical or learning disabilities)
- Life experiences and knowledge
- The environment they live in (e.g. city or rural area).

For example, a young child might learn how to play and explore safely at home, while an older child might be learning how to catch a bus. As children with BBS often face progressive vision loss, early referral and planning are crucial.

What to Expect at Different Ages

The following milestones give a general sense of the types of skills habilitation can support over time. However, every child is different. For children and young people with BBS, who may also have learning disabilities, autism, and/or developmental delays, progress may follow a different pace, and that's completely okay.

- **Early Stage (typically ages 0–5):**
  Children begin learning how to move, explore, and make sense of their environment through touch and sound. Families are supported to encourage safe play, body awareness, and early self-care (like brushing teeth or toileting). Some children may be introduced to a cane or simple orientation tools.

- **Emerging Independence Stage (often around 6–8):**
  Children start to navigate familiar spaces like classrooms or corridors, use protective techniques to avoid obstacles, and complete small daily tasks (pouring drinks, using cutlery). This stage may include learning how to ask for help or beginning basic cane use, if appropriate.
- **Transitional Stage (typically around 9–11):**
  Children become more confident with daily routines. They may practice getting around school independently, prepare simple meals, learn money skills, and explore safe ways to travel. Skills around personal care and recognising public transport routines are often introduced here.
- **Adolescence to Early Adulthood (roughly 12–16+):**
  At this stage, young people are encouraged to take on more independence, using public transport, managing household tasks, advocating for themselves, and navigating real-world settings. Skills are built gradually, with ongoing support based on each individual's confidence, vision, and other needs.

Securing Support and Your Rights

If your child has an EHCP (Education, Health and Care Plan), it should include the need for regular, ongoing habilitation. Suzy shared wording often used in her reports:

"[Child] is severely sight impaired and will need to continue developing age-appropriate mobility and independent living skills. They will require regular and ongoing access to a registered habilitation specialist."

If local services are slow or refuse support, Suzy advised:

- Downloading the Quality Standards for Habilitation from HabVIUK's website
- Contacting Guide Dogs for additional help
- Challenging decisions with strong evidence (e.g., using the statement above)

What Parents Can Do

Suzy placed a strong emphasis on parents being actively involved in habilitation, and playing a vital role in helping children to become confident and independent. That starts with allowing them to try things, even when it's messy, slow, or a bit scary. Don't wrap them in cotton wool, let them learn, try, and grow. It is important to think about how much visual learning happens naturally for someone with full sight, and replicating that with tactile experiences:

- Encourage your child to explore their environment hands-on
- Encourage independence with everyday tasks, including cleaning and other household chores.
- Teach organisation skills - label drawers to help them find their clothes
- Don't be afraid of mistakes, let your child try, even if it takes longer
- Talk about sounds, touch, and smells during daily life
- Encourage your child to run and play - movement builds confidence
- Practice real-life travel routes and daily routines together

If a child becomes confident while they still have some useful sight, they'll be much better prepared if that sight reduces in the future; learning now builds confidence later - it's not just about coping, it's about thriving.

Resources:

- www.Habilitationviuk.org.uk
- Habilitation Quality Standards 2nd Edition - Habilitation VI UK
- Curriculum Framework for Children and Young People with Vision Impairment (CFVI)-RNIB

You can find links to the resources discussed as well as many more on the BBS UK website.

Conference feedback

Your feedback is vital to the success of our conferences and is something we come back to year on year in our planning and development. Thank you to everyone who completed an evaluation form.

Here's a summary of your feedback:
93% said they felt better informed about research
84% said their reasons for attending were 'met'
71% rated the location and venue as 'good' or 'very good'
69% said they had a better understanding of BBS and how to manage it
63% Said they felt more connected to the BBS community and less isolated

Comments received:

"…such a well organised and well run event that we look forward to attending as we know that we don't have to worry about anything - all members of the family are catered for. This is such an amazing and priceless event. Long may it continue!"

"The bringing together of so many families and individuals affected by BBS with specialists knowledgeable about all aspects of the syndrome is an amazing achievement. This fantastic level of cooperation should be a model for other rare syndromes."

"Attending BBS conference for the first time was such an amazing experience I was able to meet many lovely people. The conference made me feel so happy [about] how much of a community we are. I'm forever grateful for being a part of this community. I'll be coming every year now to conference."

"Our family loves to come to the conference. As a family it gives us some fun time together and we love to meet and chat with other families who go through the same as we do. The BBS team always give their best to make this weekend special for everyone."

Thank You

Our heartfelt thanks go to the incredible speakers who generously gave their time to share their insights, expertise and research. We are especially grateful to those who shared their inspiring personal perspectives, which resonated so well with us all.

Our thanks also to our wonderful BBS UK team of staff and trustees for their commitment and efforts throughout the year that enable us to put on such high-quality events.

Most importantly, we thank all of you, who continue to support our work, and give so much back to the BBS community. We hope that you have all learned something that will help or inspire you in your day to day lives as someone living with the Syndrome or supporting someone with BBS, personally or professionally; it is uplifting to know that there is such a large community eager to learn, share experiences, support each other and work together to make life better for those with Bardet-Biedl syndrome.

Our annual conference and all the other services we provide really are invaluable and rely on your donations and fundraising – if you would like information on how to donate or support the work that we do, visit the BBS UK website.

SAVE THE DATE!!

BBS UK Conference 2026 will be held, in-person, across the weekend of **25th-27th September 2026.**

We will once again be live-streaming the event on Saturday 26th September, so if you cannot attend in-person, you can still join us by watching and listening through the livestream. Further announcements to come in 2026!

Fundraising: we need your help!

We're calling on you, our amazing BBS UK community, to help us raise funds to keep our services going. By donating money or organising a fundraising event, you can contribute towards our:

- **Advice Service** – a support and advocacy service that helps people with BBS to access the local support they need across health, education, and social care, including negotiating support packages, helping with housing issues and benefits applications, and with future planning.
- **Annual family conference weekend** - brings members of the community together with interested professionals and experts to provide updates on the latest research and the opportunity to participate in tailored workshops.
- **Newsletters and conference report** - provides up-to-date research, information, guidance, personal perspectives, and details of our projects and fundraising activities.
- **Publications** - including our Medical Booklet, Introducing BBS and Booklet for Schools and Colleges leaflets which are available in various formats for accessibility.
- **Attendance at external events** – educating professionals and members of the public about BBS and BBS UK at events such as Sight Village and Retina UK.

Becoming a fundraiser is simple! Just follow these steps:

1. **Choose your fundraiser** – Marathons, cake sales, non-uniform days, sports events, quiz nights, wedding favours… the possibilities are endless! Pick a fundraiser that inspires you and fits your style.
2. **Set up your fundraising page on JustGiving** – and click on the Fundraise for Us button.
3. **Share it with the world** - Share your fundraiser with everyone you know: friends, family, colleagues, and neighbours.

Follow the link to our website for a full guide on how to become a fundraiser.

We’re excited to launch BBS UK Challenge Events!

Whether you’re looking to run a marathon, walk a scenic route, brave a bungee jump, or take on a family-friendly inflatable course, there’s a challenge for every energy level.

Choose from events such as Brighton Marathon, Manchester Marathon, Great Scottish Run 10k and more!

Pick your challenge from our website, or let us know if there’s an event you want to take part in.

Visit our website and find out all of the ways you can support BBS UK. Got questions? Email fundraising@bbsuk.org.uk and we’ll be happy to help.

Donate monthly

By making a regular monthly donation or raising funds, you will be helping BBS UK to plan ahead and make long-term developments to our much needed and highly regarded support, advocacy and information services. A regular gift allows us to plan strategically as we know day in, day out that we will have a steady income that we can rely on.

To become a Friend and regular giver:

1. Visit our website at http://www.bbsuk.org.uk/friends-of-bbs-uk
2. Complete the ‘Become a Friend of BBS UK’ online form
3. Setup a monthly standing order with your bank. Make sure to use your name as a reference so we know who to thank!

Thank you to our Friends for their generous support!

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